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ABSTRACT

This monograph reports data from a national investigation of day and vocational services for individuals with developmental disabilities provided by 50 state mental health agencies and the District of Columbia. Respondents were asked to report FY 1993 data on variables such as total numbers served, data collection systems, types and level of data collected, types of day and vocational services, referral sources and discharge placements, and information on the agency's commitment to the expansion of integrated employment. Findings from the study indicated that individuals with mental illness and developmental disabilities are being served by state mental health agencies. Data also revealed that state mental retardation/developmental agencies are the number one referral and discharge source for these individuals. The study also found that many state mental health agencies had difficulty reporting data on day and vocational service categories as defined on the survey questionnaire and the numbers served in these categories at the state level. Finally, information was gathered on states' commitment to expanding integrated employment services and their perception of barriers. The report concludes with suggestions for future research on individuals with developmental disabilities served by state mental health systems. Appendices include the data collection instrument. (Contains 22 references.) (Author/CR)

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National Study of Day and Vocational Services for Adults with Disabilities in State Mental Health Agencies:

Report of Data from FY 1993

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Institute For Community Inclusion / UAP
Children's Hospital, Boston and
University of Massachusetts, Boston

National Study of Day and Vocational Services for Adults with Developmental Disabilities in State Mental Health Agencies: Report of Data from FY 1993

November, 1996

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This study was funded in part by grant #90DD-0346 awarded by the Administration on Developmental Disabilities to the Institute for Community Inclusion, Children's Hospital , Boston. The opinions expressed in this study are exclusively those of the staff of the Institute for Community Inclusion. No official endorsement by the Administration on Developmental Disabilities should be inferred.

National Study of Day and Vocational Services for Adults with Developmental Disabilities in State Mental Health Agencies: Report of Data from FY 1993

Abstract

This monograph reports data from a national investigation of day and vocational services for individuals with developmental disabilities provided by state mental health agencies. Investigators asked 50 state Mental Health (MH) agencies and the District of Columbia to report FY 1993 data on variables such as: total numbers served, data collection systems, types and level of data collected, types of day and vocational services, referral sources and discharge placements, and information on the agency's commitment to the expansion of integrated employment. Findings from the study indicate that individuals with mental illness and developmental disabilities are being served by state mental health agencies. Data also revealed that state Mental Retardation/Developmental Disability (MR/DD) agencies are the number one referral and discharge source for these individuals. In addition, this preliminary study found that many state MH agencies had difficulty reporting data on day and vocational service categories as defined on the survey questionnaire and the numbers served in these categories at the state level. Finally, information was gathered on states' commitment to expanding integrated employment services and their perception of barriers to this effort. The report concludes with suggestions for future research on individuals with development disabilities served by state mental health systems.

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The 1990's has been a time of change and uncertainty for state-administered disability services. In 1989 the Mental Health Reform Act emphasized community inclusion and use of local support and resources, which "represented a change in treatment philosophy" (Semke et al., 1994, p. 74). The Americans with Disabilities Act (P.L. 101-336) became law in 1990 followed by the reauthorization of the Individuals with Disabilities Education Act (IDEA) in 1991 (P.L. 102-119) and the 1992 Rehabilitation Act Amendments (P.L. 102-569) all of which laid the ground work for increased access and opportunities within the community for individuals with disabilities. With this wave of legislation, state agencies have been charged with implementing these disability laws while facing considerable fiscal constraints and programmatic changes. Concurrently, the nation as a whole has been involved in preparing for the possibility of block-grant funding of state-run human service agencies and the debate over balancing the federal budget. The Mental Health service system has become especially involved in health care reform debates and the movement to managed care. The impact of these issues on state disability service agencies has been tightened fiscal planning and the development of plans for redesigning state agencies (Callahan, 1994; Kane, 1993; Lutterman, Harris, O'Brien, Bozynski, & Hollen, 1995).

Organizational Issues

Within this broader context of change and uncertainty, the field of mental health services has seen a series of changes and reform efforts in and of itself over the last twenty years. The increasing emphasis on community-based, day treatment and residential services has, some believe, set the stage for polarization between hospital and community service settings, which can be seen in the organizational structure of mental health services in states (Lutterman et al., 1995; Mechanic, 1994). Funding and coordination of public mental health services primarily happens at the state level while service delivery and the day-to-day management of community mental health systems occurs at the county, regional, and/or local level (Lutterman et al., 1995). Additionally, state mental health

agencies increasingly take on the role of primary service provider for the poor and those with the most severe mental illness (Lutterman et al., 1995). The expansion of services and treatment programs through private providers has also contributed to the general decentralization of mental health services and "shortfalls…in the treatment of severe mental illness" (Sharfstein, 1993, p. 115). In addition to the organizational difficulties, the consumer and family empowerment movement of the last ten to fifteen years has also contributed to greater control of service delivery at the local level and to what Kane (1993) calls a "power shift from government and professionals to consumers" (p. 104). These organizational issues have had considerable impact on the role state mental health agencies play in the delivery of mental health services and the collection and availability of service data at the state level. As a result of this decentralization, the state level agencies often can not report service or even expenditure data for their state (Lutterman et al., 1995).

As the shift to decentralized service administration has taken place, the role and mission of state agencies has developed in two ways. First, under the influence of consumer advocacy efforts and federal legislation, more and more emphasis was placed on providing appropriate community-based services to the elderly, ethnic minorities, and the chronically mentally ill (Semke et al., 1994). There is evidence, however, that the numbers of individuals from target populations, many of whom need services the most, have not increased and the mandate set forth by the Mental Health Reform Act may still be largely unfulfilled (Semke et al., 1994). The second effect is seen in the fact that state mental health agencies are "becoming the funder of last resort, insuring coverage to persons with the most severe mental illnesses and providing care for people without health insurance or for whom insurance has expired or been exhausted" (Lutterman et al., 1995, p. 3). Thus, we see a continuation of the polarization between state and community mental health services that developed in the 1960's and 1970's (Mechanic, 1994). This polarization may be characterized by state agency management of facility-based and crisis-related services for

the most severely disabled while community-based services function fairly autonomously and deliver a broader range of service options (Sharfstein, 1993).

Service Options

The services provided or funded through state mental health services have traditionally focused on treatment for the medical aspects of mental illness and crisis intervention. In the 1960's and 1970's, however, increasing awareness grew of the need for a broad spectrum of services and a corresponding set of strategies developed to meet the social, residential, and vocational needs of individuals with mental illness in their communities. In 1989 the Mental Health Reform Act affirmed expectations to expand the range of mental health services at the local level, including medication management services, vocational services, crisis response services, and substance abuse treatment services (Semke et al., 1994). Current treatment and service models within the Mental Health service realm now can be categorized as the more medically based models and the more clearly psycho-social models. The medically based services include: day treatment , day habilitation, and hospitalization. Examples of the psycho-social treatment models include: clubhouses, Assertive Community Treatment, social skills training, and Fairweather Lodge (Marrone, 1993). The psycho-social service delivery models influenced the development of integrated employment options, ongoing support systems, and the "acceptance of seriously disabled clients as capable of paid work" (Anthony & Blanch, 1987, p. 9). Despite the expansion of mental health services, vocational rehabilitation within the mental health sector has never enjoyed the attention that these services have received within the MR/DD service sector (Anthony & Blanch, 1987). There is, however, growing interest and implementation of vocational services in the mental health field including psycho-social rehabilitation approaches, transitional employment programming, the psychiatric rehabilitation movement, the community support movement, and supported employment methodology (Marrone, 1993).

Barriers to the development of supported and other integrated models of employment for individuals with mental illness remain. Anthony and Blanch (1987) describe personnel, program, and systems barriers that stand in the way of wide use of supported employment within mental health services. Examples of personnel barriers include low pay, high turnover, lack of expertise in supported employment technology, and job requirements such as unusual flexibility and commitment. Program and personnel barriers include such things as: a general lack of start up dollars, limited data on pilot programs, the labor intensive nature of supported employment, the need for extensive training, and a general lack of experts in the field. Finally, systems barriers include variables such as large caseloads, a lack of collaboration between Departments of Vocational Rehabilitation (DVR) and state Mental Health (MH) agencies, and a lack of state level commitment. While these personnel, program, and systems barriers may not be unique to the MH service system, they certainly stand in the way of full implementation of supported employment.

Populations Served

Although serving those with the greatest need has become a focal point in the mission statements of state vocational rehabilitation services (In the Public Interest, 1992) and state mental health services (e.g., Mental Health Reform Act of 1989), their definition of who has the greatest needs varies. In the field of mental health, individuals with chronic and persistent mental illness are typically considered as those most in need. Certainly adults whose mental illness was diagnosed during the developmental period of childhood and has continued into adult life fit this definition of chronic and persistent mental illness. Likewise, those with the dual diagnoses of mental retardation and mental illness are likely to be considered severely disabled as well. Even when severe disabilities are identified, questions remain as to where these individuals are best served or even being served. Very little is known about the extent to which individuals with developmental disabilities and/or mental retardation are being served through state mental health agencies. What is known of

this group has been investigated from the perspective of development disabilities or mental retardation as the primary diagnosis and data has been collected through the state MR/DD agencies or community-based programs that primarily serve individuals with mental retardation (Borthwick-Duffy, 1994; Borthwick-Duffy & Eyman, 1990; Reiss, 1990). Reasons for this lack of information may be the traditional assumptions that mental retardation is automatically assumed to be the primary disability, individuals with mental retardation are not expected to suffer from mental illness (Borthwick-Duffy et al., 1990;), or professionals do not have the diagnostic tools, experience, and training to identify the specific nature of problems for individuals with mental retardation and mental illness (Jacobson, 1990).

The current investigation was conducted to complete a national profile of how and where individuals with developmental disabilities including mental illness and/or mental retardation received day and vocational services through state MH agencies. The current study was designed to complement on-going investigations also being conducted through the Institute for Community Inclusion and funded by the Administration on Developmental Disabilities that together paint a national picture of integrated employment services for individuals with developmental disabilities (Kiernan & Schalock, in press; McGaughey, Kiernan, McNally, & Gilmore, 1993; McGaughey, Kiernan, McNally, Gilmore, & Keith, 1994). In the current atmosphere of reform and restructuring, the current study and its companion works seek to provide a snapshot of the range of employment outcomes for individuals with disabilities and examine trends to promote and implement integrated services for such individuals. This study will contribute to efforts documenting and measuring the effects of reform, interagency cooperation, and consumer inclusion in community life. The specific purpose of this study was to gain an understanding of day and vocational services through state MH agencies for individuals who are considered to have developmental disabilities related to mental illness as well as those with dual

diagnoses of mental retardation and mental illness. In order to accomplish this purpose this study explored the following research questions:

- What proportion of the total number of people served through MH agencies are considered to have developmental disabilities related to mental illness as well as those with dual diagnoses of mental retardation and mental illness?
- What are the day and vocational services being offered, funded, and administered by state MH agencies?
- What are state MH agencies' commitments to expanding integrated employment?

Methods

This research was designed to be exploratory and descriptive. The broad research questions represent a first foray into FY 1993 services and descriptions of consumers served through day and employment services in the state mental health service delivery system. It was not the intentions of the researchers to test hypotheses or generalize the information gathered to a population beyond the confines of this investigation.

Participants

Respondents. In August of 1994 a letter inviting participation and a sample of the questionnaire requesting information on community-based day/employment service trends for FY 1993 were mailed to the commissioners or directors of 51 state Mental Health Agencies and Washington, DC. (For a copy of this letter, see Appendix A). Commissioners were asked to nominate an individual within the agency who had knowledge of state-level service and policy data and who would serve as survey coordinator for the study. Commissioners returned a postcard with the nominee's name, address and title and all subsequent communication took place between the survey coordinators and the first and second authors. The survey coordinators included: directors of data analysis and research, research analysts, research managers, chiefs of vocational branch, MH bureau chiefs, and directors of communications.

Follow-up. In the middle of September, 1994, a second mailing to the Commissioners went out reminding them of our request for participation. Following this mailing, 50 out of 51 (98%) agencies had named survey coordinators. Questionnaires were mailed to the survey coordinators as names and addresses were received. Two reminder letters were mailed to the survey coordinators in October and November, 1994. Over the Spring and Summer of 1995 telephone follow-up was conducted with non-respondents. As responses came in and were entered, cleaning procedures began. In October, 1995, the Commissioners and Directors were sent a summary with the data that had been collected from their state. They were asked to confer with their survey coordinator and provide missing data. Omissions and irregularities were clarified through telephone and fax contact with the survey coordinators. At the time of analysis, the final response was 42 agencies out of 51 agencies for an 82% response rate (see Appendix B for a complete list of states, commissioners, and data coordinators who participated in this project).

Instrumentation

The questionnaire used was developed specifically for this study. Items were written and adapted from similar questionnaires used to gather information from the state Mental Retardation/Developmental Disabilities agencies (McGaughey et al., 1993) and from a national sample of facilities providing day and vocational services to individuals with disabilities (McGaughey et al., 1994). Preliminary versions of the questionnaire were reviewed by a panel of professionals with expertise in day and vocational services, state agency system management, and state mental health service delivery (DeVellis, 1991). A copy of the questionnaire used in the current study is included in Appendix C.

Results

State Data Collection Systems

Respondents from state mental health agencies were asked whether or not their agency had a computerized management information system to track or document

individuals served and/or services provided. Of the 41 states that responded to this question, 31 answered yes, they do have a computerized system; three said no; and seven said that a computerized MIS (Management Information System) was under development (See Table 1 for a complete list of states and their data management systems). The researchers encouraged the data coordinators to write additional information in the space provided. One of these respondents reported that their MIS was in place at the Community Mental Health Center level but under development at the state level. Another state clarified that although they do not have a centralized MIS they do have a number of databases used to collect data on service categories currently in use. Respondents that told us their state agency did have a computerized management information system were asked to describe their computer resources by checking all types of computer systems they used from a list provided on the questionnaire. 13 reported that they used a personal computer or PC network within their department. 14 reported that they have a mainframe or mini-computer within their state agency. 10 reported that their data management system is within a state umbrella agency or separate state agency. Finally, only 2 reported that they used another data management system, such as a "wide area network linking facilities to MH minicomputers" and "a server at central office networks to a regional support network (RSN) server that uses independent software systems to provide state core data."

Respondents were also asked to report the availability of data types and the level or levels at which their data are aggregated within their state. Table 2 depicts the type and level of aggregated data reported to us by the state data coordinators. The columns in Table 2 indicate the number of states that collect and aggregate data at only the state level; only the regional level; only the county level; at both the state and regional levels; at both the state and county levels; or at the state, region, and county levels. The most commonly collected data at any level include age, gender, ethnicity, primary disability, type of service by number of consumers, service category, and funding source. Given that this survey went to the state MH offices, it is interesting to consider the data aggregated at the state level. In

order to summarize this, we considered those states that aggregate data at only the state level; the state and regional level; the state and county level; and the state, regional and county level. Data in Table 2 shows that only 29 respondents reported that they collect service category data, 21 collect secondary disability, and 23 collect primary disability by service type data at the state level (if not at the region and county level as well). Given the lack of data available at the state level, it comes as no surprise that it was difficult to gather a great deal of data on the numbers of individuals served who may have mental retardation (e.g., secondary disability) when the question was asked later on in the questionnaire. Likewise, since roughly half of the state mental health agencies are able to provide information on secondary disability and service category it was difficult to gather information on numbers of individuals with and without mental retardation served in given service categories on the questionnaire.

Table 1

Responding states with MIS availability

State	Abbr.[1]	Yes	No	Don't Know
Alaska	AK	AK		
Alabama	AL	AL		
Arkansas	AR	AR		
California	CA	CA		
Colorado	CO	CO		
Connecticut	CT	CT		
District of Columbia	DC	DC		
Florida	FL	FL		
Georgia	GA	GA		
Iowa	IA			IA
Idaho	ID			ID
Illinois	IL	IL		
Indiana	IN			IN
Kansas	KS			KS
Kentucky	KY	KY		
Louisiana	LA	LA		
Massachusetts	MA			MA
Maryland	MD	MD		
Maine	ME		ME	
Michigan	MI		MI	
Minnesota	MN	MN		
Missouri	MO	MO		
Mississippi	MS			MS
North Carolina	NC	NC		
North Dakota	ND	ND		
Nebraska	NE	NE		
New Hampshire	NH			NH
New Jersey	NJ	NJ		
Nevada	NV	NV		
Ohio	OH	OH		
Oklahoma	OK	OK		
Pennsylvania	PA	PA		
Rhode Island	RI	RI		
South Carolina	SC	SC		
Tennessee	TN	TN		
Texas	TX	TX		
Virginia	VA	VA		
Vermont	VT	VT		
Washington	WA	WA		
Wisconsin	WI		WI	
West Virginia	WV	WV		
Wyoming	WY	WY		
Totals		32	3	7

[1] Abbreviations will be used on all other tables

Table 2

Category of data by level of availability[1]

Data element	Data not available[2]	State	Region	County	State & region	State & county	State, region & county
1. Expenditure data for day/vocational services							
(a) Funding source	12	11		2	10	1	6
(b) Service category (e.g. supported employment, facility based work)	14	12		2	9	1	4
2. Consumer characteristics							
(a) Age	7	10	1	2	9	1	12
(b) Gender	7	10	1	2	9	1	12
(c) Ethnicity	11	8	1	2	7	1	12
(d) Primary disability	11	10		1	8	1	11
(e) Secondary disability	19	7	1	1	5	1	8
(f) Adaptive/functional skills related to the seven major life areas	37	1	1		1		2
3. Service data							
(a) Type of service by number of consumers (e.g. number of people receiving supported employment services)	11	10		2	10	2	7
(b) Primary disability by service type (e.g. number of individuals with mental retardation in supported employment)	17	8	1	1	8	2	5
4. Unmet data needs							
(a) Number of individuals graduating who will need services	37	2		1	1	1	
(b) Number of individuals not receiving but waiting for services	29	4	2		3	2	2
(c) Number of individuals receiving services who need a different service	40			1			1

[1] Table reads across only

[2] Columns are mutually exclusive

Of note is the large number of categories in which states were not able to respond at all. The four least frequently used categories of service data were:

- Number of individuals receiving services who need a different service (n = 2).
- Number of individuals graduating who will need services (n = 5).
- Consumers' adaptive/functional skills related to the seven major life areas (n = 5).
- Number of individuals not receiving but waiting for services (n = 13).

Individuals Served

Total served. Table 3 shows the total numbers of individuals served by state mental health agencies in FY 1993 as reported by the data coordinators in each state. 37 of the 42 states that submitted responses to the questionnaire were able to report the total number of individuals who received services from their state mental health agency. These totals include people who received inpatient or outpatient services, case management, or vocational services. A number of states, however, were not able to provide us with this information. One state, for example, wrote in "we do not directly provide any services other than institutional care. By far the vast majority of [our state's] service providers are private non-profit agencies." Likewise, another state was unable to complete the questionnaire at all given the decentralization of their services, which are administered and implemented by local community mental health boards.

Table 3

Total number served by state

State	Overall	With developmental disabilities	With mental retardation	In vocational services
AK	8,948	--	--	--
AL	81,592	--	6,545	241
AR	60,000	1,500	1,000	6,000
CA	339,000	--	5,000	25,000
CO	34,698	9,299	195	--
CT	16,524	1,322	131	--
DC	7,343	--	100	617
FL	264,124	--	--	--
GA	172,149	--	15,884	6,562
IL	142,471	--	--	11,245
IN	130,000	--	--	--
KS	72,777	--	7,836	1,350
KY	115,160	--	727	381
LA	47,603	4,241	790	--
MD	44,000	--	800	4,6000
ME	280	--	--	280
MN	22,790	--	--	--
MO	94,909	--	18,060	1,911
MS	68,332	--	8,577	3,467
NC	181,106	6,570	8,098	--
ND	21,601	--	1,787	1,150
NE	29,215	--	--	1,050
NH	22,278	--	--	1,235
NJ	205,914	--	3,706	11,000
NV	12,616	50	20	20
OH	283,796	--	6,846	3,466
OK	76,941	15,749	1,539	11,153
PA	180,000	--	--	26,556
RI	19,080	871	126	1,920
SC	85	--	85	--
TN	70,243	1,872	1,796	5,378
TX	148,053	--	--	--
VA	193,502	--	21,645	5,996
VT	15,512	--	69	1,844
WA	75,420	--	--	--
WI	95,513	--	--	9,445
WV	30,000	--	--	--
WY	10,147	--	11	--
Totals	3,394,902	41,474	111,373	139,947

A number of other states that were able to report total numbers served did so with qualifications. These states told us that the numbers they reported reflect some duplication between community and hospital services and those served on an inpatient and outpatient basis or that admissions numbers were complicated by factors such as: open cases prior to 6/30/92; "an individual is counted each time they are admitted;" and individuals receiving services but who are not formally admitted into the system. Another state wrote in that the number they reported does not include alcohol and drug services administered and funded by their Department of Mental Health. Similarly, one state cautioned that there are an additional 2,000 - 4,000 consumers not in their management information system but did not clarify the reason.

Individuals in vocational services. States were asked to report the total number of individuals receiving vocational services funded through the mental health agency. As is evident from Table 3, fewer states were able to provide the number of individuals who received vocational services in FY 1993 than total numbers served. A few states wrote in reasons as to why they could not report these data, including: data not being available for that time period, the respondent being hesitant to report numbers he or she did not feel were comfortably accurate, and a mismatch between the state's vocational service definitions and those listed on the questionnaire.

Individuals with developmental disabilities and mental retardation. In order to gather data on the number of individuals with developmental disabilities and/or mental retardation, states were asked to report the number of individuals with mental illness who meet the federal functional definition of developmental disabilities as the result of a psychiatric disability and the number of individuals served by the MH agency who have mental retardation according to the definition in the DSM IV (See Table 3). Appendix D includes the diagnosis definitions that were enclosed with the survey questionnaire. These definitions are: the Center for Mental Heath Service's definition of mental illness, the federal functional definition of developmental disabilities, and the 1992 American

Association on Mental Retardation's definition of mental retardation. It was anticipated that the number of individuals with mental retardation would be a subset of individuals with developmental disabilities. Data on the total number of individuals with developmental disabilities served by MH agencies were only available from nine states. Although we asked for estimates if actual numbers were not available, only two states explicitly noted that the numbers they gave were estimated. Two states provided a percentage of the total number they serve as being an estimate of the number of individuals with developmental disabilities. The researchers used these percentages to calculate the estimated number of individuals with developmental disabilities served in these states. However, the researchers were not able to calculate an estimate for another respondent who wrote:

> Anecdotal estimates range from 20% to 50% to 90%. The range is explained by the different service pockets examined. No one is comfortable offering a system-wide estimate. I am comfortable saying that the number of persons in [our state] with a psychiatric disability who would meet the federal definition of developmental disability is not [sic] significant.

Two states explained that the numbers they report needed to be clarified for definitional reasons. One state said that the number reported is the number of people classified as those with "disorders of childhood" while another state reported that the 15,749 estimated were those individuals identified as having severe and persistent mental illness (SPMI) and cautioned the researchers "that [our state's] definition of SPMI may not specifically match the federal DD definition." One state wrote in that the federal definition for developmental disabilities was not in use in their state until July, 1994. Finally, another respondent wrote that it is the responsibility of the state Department of Developmental Services to serve people who meet the definition of developmental disabilities. Nevertheless, this respondent felt that some people with developmental disabilities may also get mental health services, but declined to estimate how many individuals this might be.

A greater number of states (24) were able to provide the total number of individuals who have mental retardation and receive services from the MH agency. Three of the states that could not report totals wrote the following explanations. One said that they just started gathering these data and it was incomplete at the time of the questionnaire. A second state explained that:

> mental retardation services and mental health services are administered through different divisions of the same agency…Generally, persons who are dually diagnosed (Mental Health/Mental Retardation: MH/MR) receive services through the mental retardation service structure. Significant exceptions include persons in Multiple Disability Units of state hospitals.

The data coordinator from this state went on to say that data on the number of individuals served with an MH/MR diagnosis would be very difficult to develop. The third state was able to report that 268 individuals with mental retardation were served in FY '94, but data were not available for FY '93. Three additional states were able to provide total numbers served but clarified their responses. For these clarifications, see the technical notes in Appendix E.

Referral and Discharges for Individuals with Mental Retardation/Developmental Disabilities

In order to understand how individuals with mental retardation/developmental disabilities gain access and are discharged from inpatient services in the MH agency, we asked respondents to rank order the most frequent referral and discharge sources. Only 12 states could report the relative frequency of referral and discharge source. Four states reported only referral sources and two states could only tell us about discharge placements. Figure 1 depicts the mean rank along a scale in which 1 represents the most frequent referral source. The means can be interpreted with the understanding that the closer the mean rank is to one the more likely it was chosen as a frequent referral source. For example, the most frequent referral source for individuals with MR/DD to MH inpatient services are MR/DD agencies. The second most frequent referral source are the courts.

Based on the mean ranking alone, the least likely referral source are schools. A few states reported other referral sources that were not listed on the questionnaire. These sources include: hospital, general as well as psychiatric; community mental health centers, shelters for the homeless, concerned people, and the consumer.

Figure 1

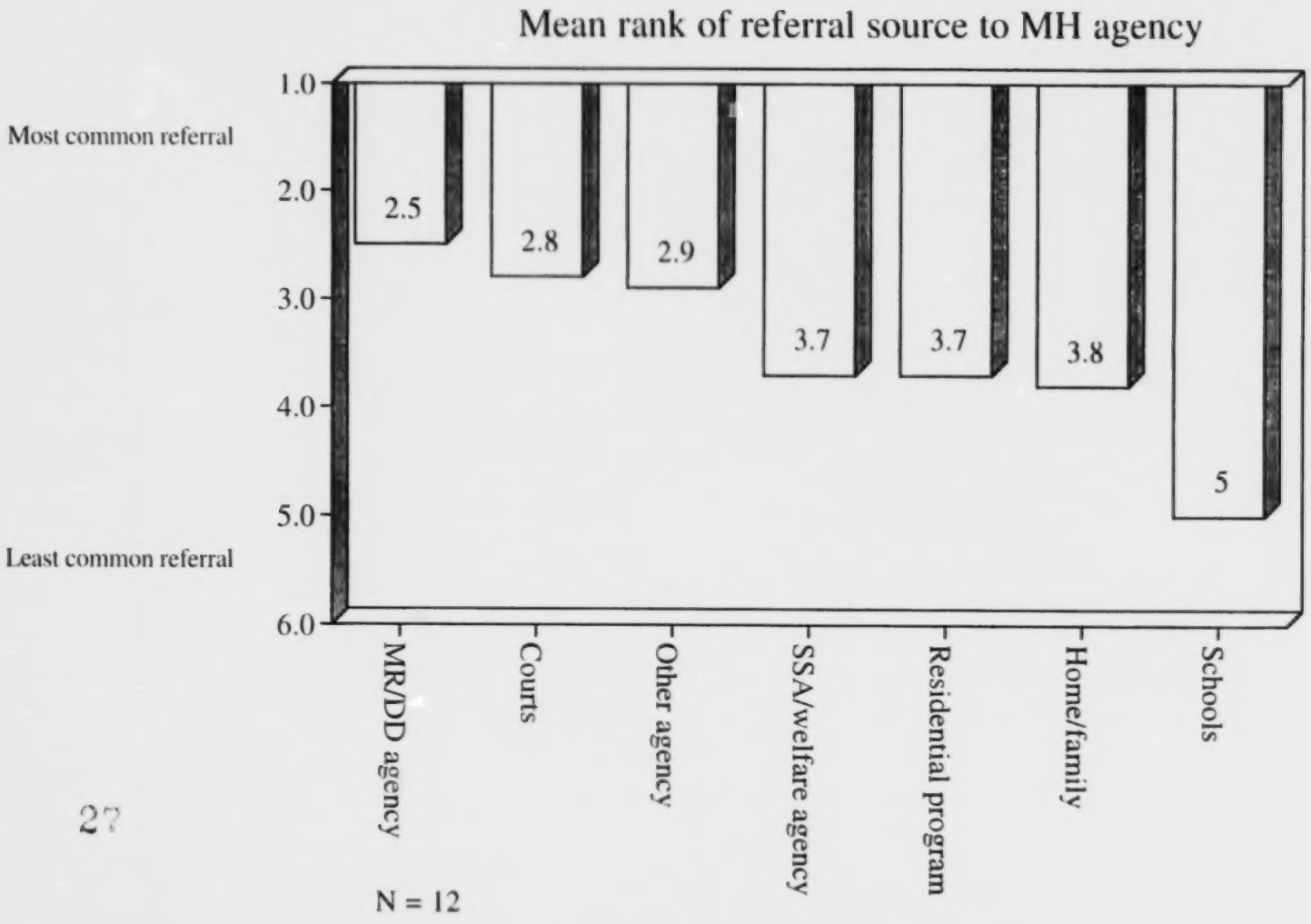
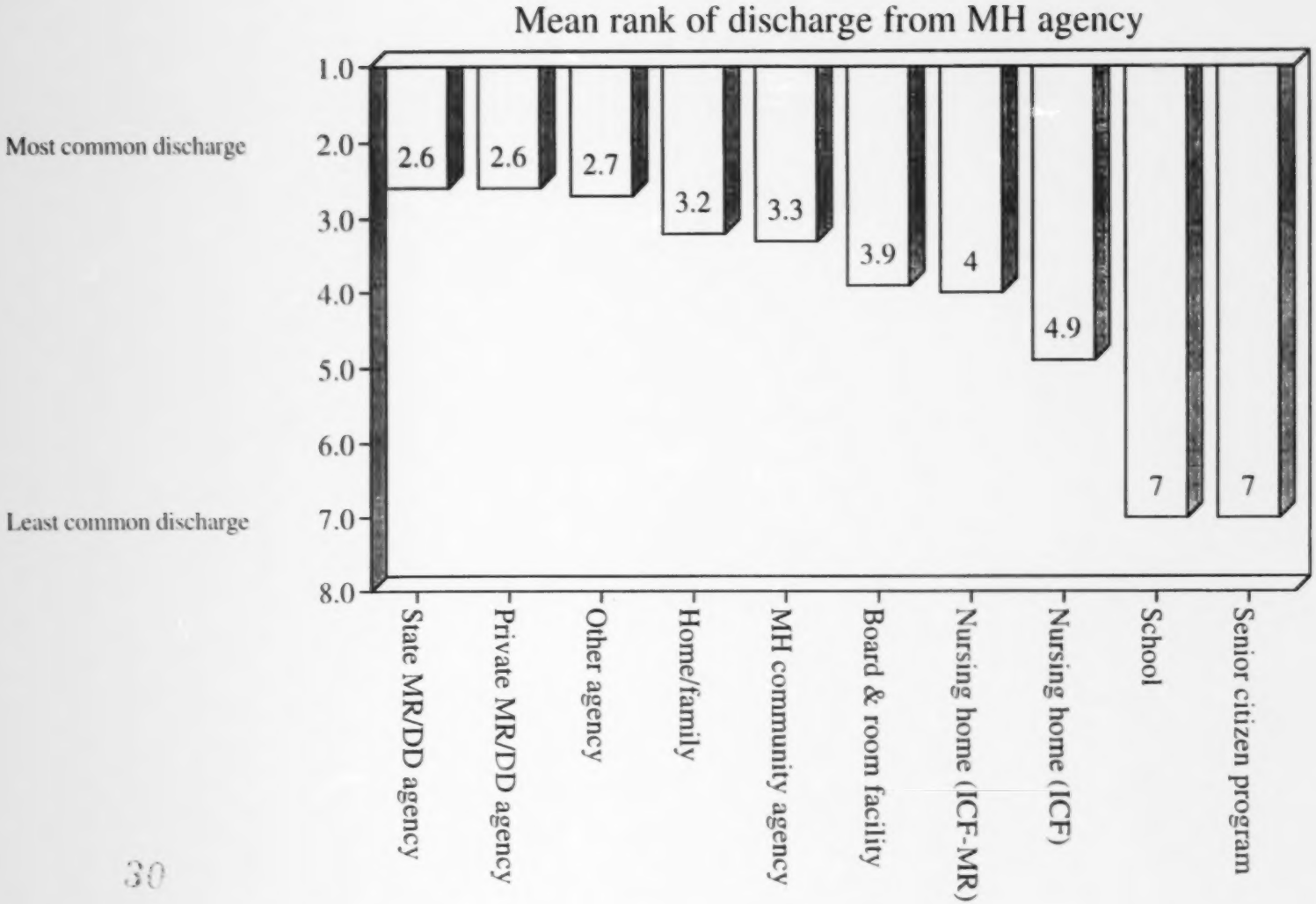

Mean rank of referral source to MH agency
Most common referral
Least common referral
1.0
2.0
3.0
4.0
5.0
6.0
2.5
2.8
2.9
3.7
3.7
3.8
5
MR/DD agency
Courts
Other agency
SSA/welfare agency
Residential program
Home/family
Schools
N = 12

Figure 2 depicts the frequency of discharge placements in a manner similar to the referral source data. As in the case with the referral data, the two most frequent discharge placements for individuals with MR/DD after inpatient services are state or private MR/DD agencies. The next most frequent discharge placement were reportedly other agencies, which include: contract providers, group homes, community mental health centers and outpatient facilities, the justice system, out-of-state placements, MH foster care, MH residential treatment centers, special private placements, and the consumers own home or apartment. The two least frequently used discharge placement are the schools and senior citizen programs.

Day and Vocational Services

The questionnaire asked the data coordinators to report the type of community-based day and vocational services funded, operated, or regulated by the MH agency and the number of individuals served in each of the service categories. The data coordinators were asked not to report services that are conducted on the grounds of residential mental health hospitals or facilities that serve more than 16 individuals. A complete definition of each day and vocational service category on the questionnaire was provided for the respondents (See Appendix D). Table 4 depicts services offered by state.

Figure 2



N = 12

ICF = Intermediate Care Facility, ICF -MR= Intermediate Care Facility for the Mentally Retarded

Table 4

Day and employment services offered

State	Competitive employment	Supported employment	Clubhouse	Facility-based work	Facility-based nonwork	Elderly programs
AK	AK	AK	AK	AK	AK	AK
AL	AL	AL		AL	AL	
AR	AR	AR	AR	AR	AR	
CA	CA	CA	CA	CA	CA	CA
CO	CO	CO	CO	CO	CO	CO
CT		CT	CT		CT	
DC	DC	DC	DC	DC	DC	DC
FL	FL	FL		FL	FL	FL
GA	GA	GA	GA	GA	GA	GA
ID	ID	ID			ID	
IL		IL			IL	IL
KS	KS	KS	KS	KS	KS	
KY		KY	KY	KY	KY	KY
LA			LA	LA	LA	
MA	MA	MA	MA	MA	MA	MA
MD		MD	MD	MD	MD	MD
ME	ME	ME			ME	ME
MN	MN	MN	MN	MN	MN	MN
MO	MO	MO	MO	MO	MO	MO
MS	MS	MS	MS	MS	MS	MS
NC		NC	NC	NC	NC	
ND		ND	ND	ND	ND	
NE	NE	NE	NE	NE	NE	NE
NH	NH	NH	NH	NH	NH	NH
NJ	NJ	NJ	NJ	NJ	NJ	
NV	NV				NV	
OH	OH	OH	OH	OH	OH	OH
OK	OK	OK	OK	OK	OK	OK
PA	PA	PA	PA	PA	PA	PA
RI	RI	RI	RI	RI	RI	
SC	SC	SC	SC	SC	SC	
TN	TN	TN	TN	TN	TN	
TX	TX	TX	TX	TX	TX	
VA	VA	VA	VA	VA	VA	VA
VT	VT	VT	VT	VT	VT	
WA	WA	WA	WA	WA	WA	WA
WI	WI	WI	WI	WI	WI	
WV	WV	WV	WV	WV	WV	
WY		WY			WY	
Totals	31	37	32	27	39	21

Each of the thirty-eight states that could provide service category data reported that they provide facility-based, non-work programs. The second most widely available day or vocational service is supported employment, followed by clubhouse services, competitive employment, facility-based work, and programs for the elderly. When respondents were asked to report numbers of individuals who receive these services only 24 were able to provide data (See Table 5 for Total Served by Service Category). It is interesting to note that while 38 states report that they provide facility-based non-work services, only 10 states could report the total number of individuals served in this category. Numbers of individuals in supported employment and clubhouse services were the two categories in which the most data were available. Although these numbers are not generalizable, they seem to suggest that the greatest number of people are being served in facility-based non-work, clubhouses, and supported employment. This may reflect the greater emphasis on psycho-social and general rehabilitation within the MH system than an emphasis on specific employment services.

There are a number of reasons that cause us to be hesitant about generalizations of these numbers even to other MH agencies. First, a number of the states that could not supply us with data reported that their service categories do not match the service categories stipulated on the questionnaire. Secondly, decentralization of mental health services plays a role in the availability of data. For example, the state Mental Health agency in one midwestern state has given full budgetary control to the Community Mental Health Boards that administer service delivery. As a result, this is one state that could not respond to our survey at the level from which we were gathering data.

Table 5

Total number served by service category by state[1]

State	Competitive employment	Supported employment	Clubhouse	Facility-based work	Facility-based nonwork	Elderly programs
AR	50	200	1,000	200	4,000	100
CT	--	2,357	6,477	--	--	--
DC	--	70	413	--	--	--
GA	320	367	57	23	--	--
ID	0	--	0	--	--	--
IL	--	635	--	--	10,426	184
KS	--	1,350	--	--	--	--
KY	--	209	2,336	172	--	80
LA	--	--	1,584	--	--	0
MD	215	121	--	--	4,600	--
MO	--	437	6,341	--	--	519
MS	--	--	3,467	--	--	--
NC	--	--	3,265	--	6,220	--
ND	--	465	1,265	--	--	--
NE	--	73	977	--	--	--
NV	670	0	0	0	2,322	0
PA	--	2,827	--	1,904	21,825	--
RI	55	323	830	49	433	230
TN	--	682	890	79	4,784	--
TX	--	--	--	--	--	0
VA	--	2,672	4,947	2,661	5,088	--
VT	150	460	541	0	614	0
WI	2,497	228	--	1,212	--	--
WY	--	0	--	0	--	--
Totals	3,957	13,476	34,390	6,300	60,312	1,113

[1] For full definition of each service category see appendix D

Integrated Employment Policy

The final section of the questionnaire was entitled Policy Issues and asked participants to report information on their state's current policy and future commitment to the expansion of integrated employment. When asked if their state currently has a formal plan or state-level policy to expand integrated employment for persons with mental illness, 18 states (42%) said that yes, while 23 (53%) said no, and two (5%) did not respond. The two states that did not respond to this question explained that decentralized services prevented them from answering. One of these two states explained that their MH agency has "a memorandum of understanding with DVR to work on the issues." The second state, who reported that they did not have a formal plan yet, wrote in that currently there are "efforts at the local level to coordinate employment activities and establish plans."

As a follow-up to the question about a formal state plan to expand integrated employment, states with a plan or policy were asked to give projections for the numbers of new integrated employment placements over two years and five years. Of the 18 states that said they had a formal policy, only 6 were able to provide two and five year projections for new integrated placements. The overall mean number of new placements that these six states anticipate over the next two years is 2,105 (ranging from 45 - 9,651). The mean number of new placements that these six states anticipate over the next five years is 34, 071 (ranging from 250 - 193,026). Respondents were asked to explain how funds would be allocated for their expansion of integrated employment. Two of the six states reported that their state agency plans to use only new dollars for the expansion, one state said that they planned to redirect existing dollars, and three states reported that their agency would use a combination of new and redirected funds.

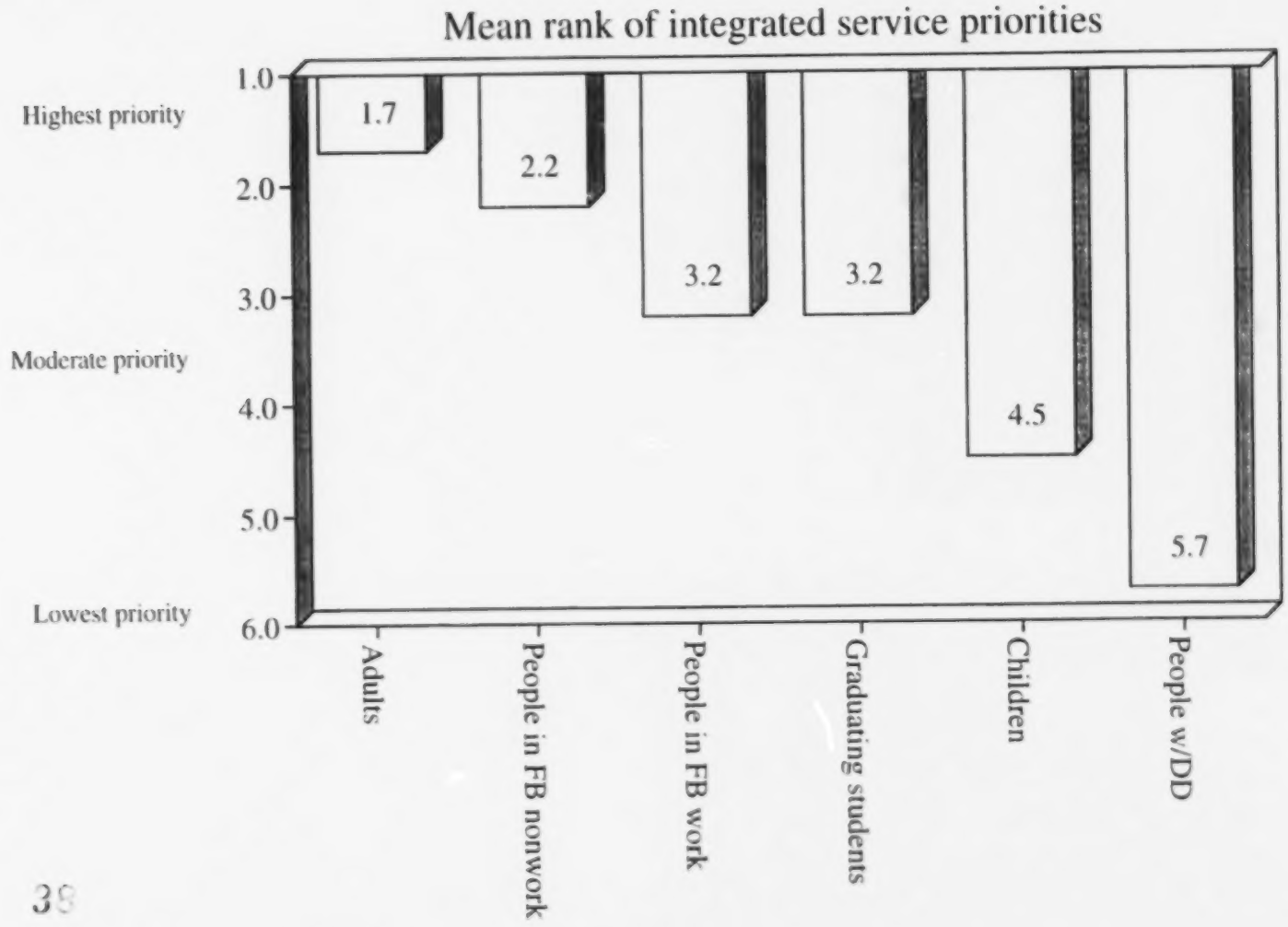
Respondents were asked if their agency has a state-level policy to prioritize or target specific groups for the allocation of integrated employment services. Ten states responded that yes, they do have a specific policy; 29 said, no, they do not have such a policy, and four did not respond to the question. Those that reported having a state-level policy were

given six priority groups for integrated employment services and an open ended "other" category (See Data Collection Instrument in Appendix C). Respondents were asked to indicate, on a seven point scale, their state's priority groups for integrated employment services with 1 being the top priority (See Figure 3 for the rank of integrated service priorities). Nine out of the ten states that had a formal policy ranked the following groups as priorities. New adult referrals into the day/employment service system had a mean ranking of 1.7. Individuals currently employed in day activity/day habilitation programs had a mean rank of 2.2. Individuals currently employed in sheltered employment/work activity programs had a mean rank of 3.2 as did students transitioning from school to work. Children with serious emotional disturbance had a mean rank of 4.5. Finally, individuals who meet the federal definition for developmental disabilities had a mean rank of 5.7. Four states reported that their first priority is to a group of individuals not listed on the questionnaire. These states wrote in: adults with severe mental illness and those with the most severe disabilities but did not provide definitions of these individuals.

Barriers to the expansion of integrated employment. The final question asked respondents to list three barriers, which they perceive as standing in the way of the expansion of integrated employment services administered by their agency for all consumers. Out of the states that responded, 35 (81%) wrote in one, two, or three barriers that they perceive in their state (See Figure 4). By far the most frequent barrier cited (n = 25) was lack of funding and limited or diminishing resources. The second most frequent response (n = 8) were issues related to staff, training, commitment, and resources at the provider or service delivery level. Disincentives such as low wages and loss of SSI benefits as well as lack of clarity between state agency responsibilities (DVR, MH, Department of Employment and Training) were both listed as barriers (n = 7 each). Listed next was the social stigma of mental illness in the eyes of employers and others in the community (n = 5). Both difficulty in providing continued support after job placement and perceived resistance on the part of programs that provide sheltered employment were listed

(n= 4). Respondents reported that integrated employment does not match the model or priorities of the mental health service system and that there are limited opportunities for meaningful employment (n= 3 each). Each of the following barriers was listed twice: lack of staff to implement programs, labor market factors, and too many competing priorities. Finally, the following barriers were mentioned each once: transportation, the impact of health care reform, the lack of a belief that individuals can work and desire to work, the need for new technology, resistant families, anti-government opinions, and local provider autonomy.

Figure 3

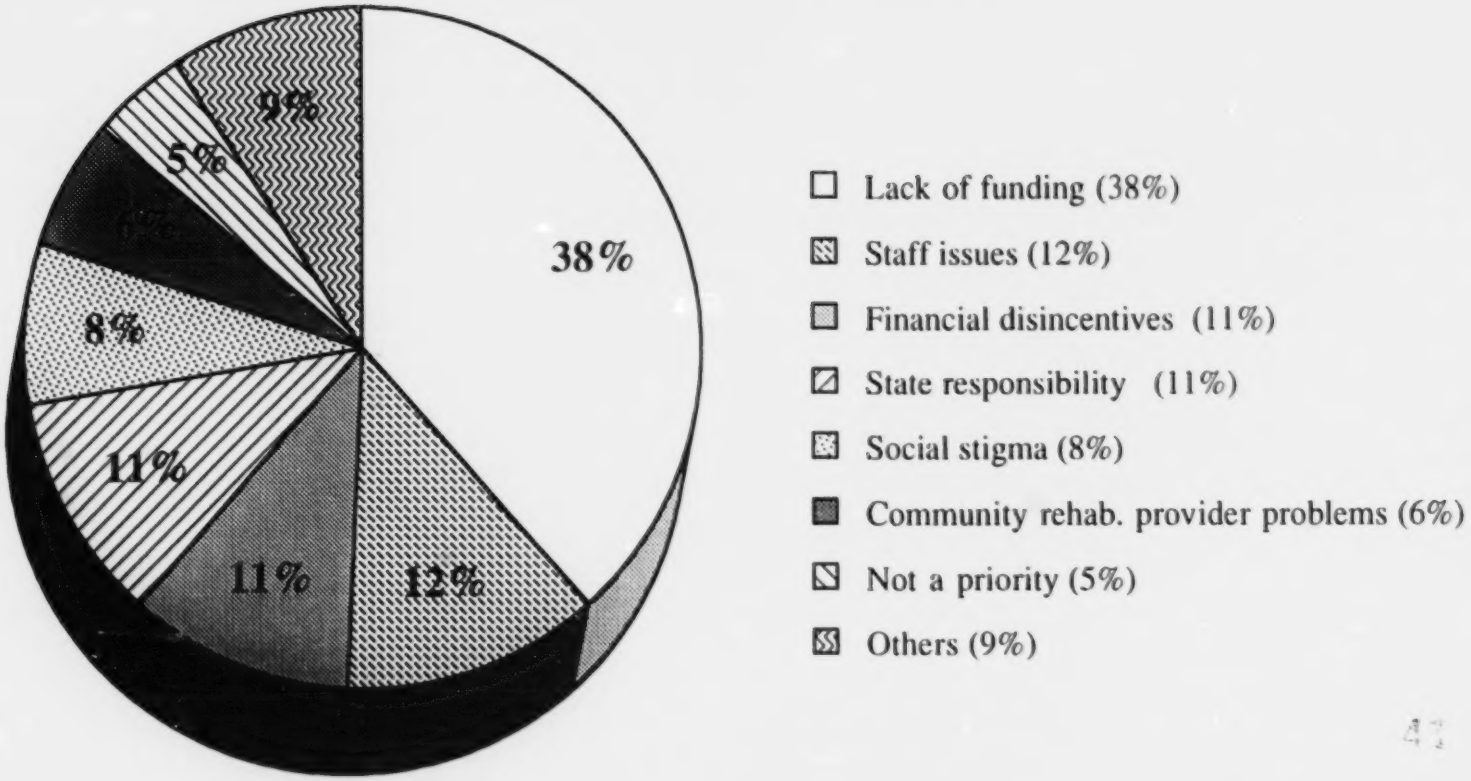


N = 9

FB = Facility-based

Figure 4

Barriers to integrated employment



N = 35

Discussion and Implications

Our collection of data about total numbers served and their referral and discharge information reveal many issues about data specific to the MR/DD population within MH agencies. First, there seemed to be considerable duplication of numbers across service providers (i.e., MR/DD agencies and MH agencies) and disability types (i.e., those with mental illness, mental retardation, and developmental disabilities). Many states do not collect data on the diagnosis of developmental disabilities or mental retardation. Those that do have limited capacity to report numbers served at the state level due to decentralized services and the diversity of services offered throughout the states. Finally, while very few states collect information on referral sources and discharge placements, it seems evident that there is a flow of individuals between the MR/DD and MH service systems. In view of the fact that many states cannot identify individuals with diagnoses of MR/DD within the MH system, it seems likely that people may be falling through the data collection cracks. This suggestion has implications for policy and planning in that it raises questions for funding, policy, and practical decision makers who may not have reliable data on the numbers of individuals with diagnoses of MD/DD within the MH system on which base their decisions.

Improvements in the organization of information at the state level are necessary to generally increase accountability, enhance quality service delivery, and remain responsive to issues and priorities in the field (Schalock, Kiernan, & McGaughey, 1992). Recommendations to improve management information systems (MIS) within state MR/DD agencies include:

- clearly articulate policy development, program development, and program monitoring goals within the MIS;
- maintain a clear focus on shared management (provider, state, federal) and multiple data sets;

- develop standards related to reliability, simplicity, user friendliness, economy, and availability;
- validate data selection and data collection; and
- build in the following data analysis capabilities: verifying, reporting, aggregating, and evaluating (Schalock et al., 1992).

Given the multiple levels of MH service delivery, the current inconsistencies in data collection, and the universal need for state agencies to set quality standards, these recommendations are equally as relevant to state MH service systems and they were to the MR/DD audience for whom they were designed.

In terms of individuals receiving services, it is clear that individuals with mental retardation and/or developmental disabilities are, indeed, being served through state MH agencies across the country. In addition, these agencies provide, fund, or administer a wide variety of day and vocational services. The greatest number of people are being served in facility-based non-work services with the second largest group of consumers receiving supported employment followed by clubhouse model services. This finding seems to mirror findings in other studies of day and vocational services that indicate a greater number of individuals with disabilities being served in segregated settings despite the continued growth of integrated work options (Gilmore, 1995; McGaughey et al., 1993; McGaughey et al., 1994).

Although 18 states reported that they have a formal plan to expand integrated employment service, the majority of the responding states (n = 23) said there was no such policy. The barrier that stands above all the others mentioned is lack of funding. In this time of budget battles and revision of funding streams there is general concern for the integrity of funds earmarked for human services (Institute for Community Inclusion, 1992). The atmosphere at the state agency level is one of protecting existing services rather than expand or even make commitments to expansion at the current time (Anthony & Blanch, 1987).

It is also notable that the largest service category nationally is the facility-based non-work category. Although complete descriptions of what these services entail within each state are not currently available, facility-based non-work may reflect the crisis intervention, psycho-social, and general rehabilitation services. In fact, three respondents wrote in that integrated employment is not a focus of the services funded, managed, or provided by their agency. Two other respondents answered that there are too many competing priorities, implying that funding is too limited and service priorities have to be set. It seems that for many state mental health agencies integrated employment is not one of these priorities.

As seen in the respondents' comments, integrated employment is seen as the priority of other state agencies (e.g., DVR or DET) and the relationship between the MH agencies and these others is not clear. This need for clarity of responsibility and mission has an impact not only on integrated employment services but also on delivery of services for individuals who may be eligible to receive services from either the MH system or the MR/DD system. In fact, while the states who could provide referral and discharge information reported that MR/DD and other agencies were the most common referral source and discharge placement most states were not able to report numbers of individuals with mental retardation served in their own agency. Explanations for the ambiguous lines between MH and MR/DD service systems for individuals with developmental disabilities may lie in the interaction between a number of challenges facing state agencies. These challenges include: varying agency roles, documentation difficulties, and differing program priorities. Certainly, more information is needed before we can reliably identify and fully understand the problem.

These findings are understandable given the political, fiscal, and organizational context within which this investigation occurred. The early '90's brought medical reform efforts and currently there are fiscal pressures that have resulted in movements to restructure human services. State MH agencies certainly are feeling these forces most noticeably in the areas of managed care and cost containment and in many instances are

becoming more aligned with the medical service delivery rather than other disability-related agencies. In addition to these forces for change, the consumer empowerment and control movement has influenced the mental health service delivery in ways that make the service system more community-based and more consumer controlled with psycho-social and holistic service priorities and a growing recognition of the need for life long supports for certain persons with mental illness.

The implications of these findings and changes for practice are that given the restructuring, the fiscal concerns, and the growth in community-based services there is an increased need for communication between service agencies in order to clarify responsibilities, establish a common language of services and definitions, and to develop mechanisms to insure that those who need services receive them and in a way that best suit their needs. In order to address this need for increased collaboration and efficient resource utilization the One-Stop Career Centers were conceived "to remedy the fragmentation and overlap in US employment services" (Connolly, 1996, p. 1). In 1995, a total of 16 states received funds from the Department of Labor to implement One-stop Centers. These centers are designed to offer a full spectrum of employment services and be available to all job seekers. The development of the One-stop Centers was initiated at the federal level and passed along to states to decide upon and design the way individual centers will provide universal services. Currently, public Vocational Rehabilitation (VR) agencies are involved in oversight in all 16 of the implementation states. These lone representatives of the disability community, however, had to fight for their place at the planning table (Connolly, 1996). Despite the stated commitment to universality, there exist many questions as to how the One-stop Centers will serve individuals with disabilities or even what accommodations will be provided in order to insure basic levels of access. Given the promise of the One-stop Career Centers and the opportunities available to individuals with disabilities, including mental illness, three recommendations are clear for state Mental Health agencies. First, MH agencies need to clarify their roles and responsibilities relative to day and

employment services for the consumers they serve. Second, MH agency personnel should have a place at the planning and oversight table for the One-stop Career Centers in order to expand day and employment services for individuals with mental illness. Third, by taking part in the design and implementation of the One-stop Centers, MH agency personnel can influence how initial in-take, referral, and employment services are developed and ultimately delivered.

There is a continued need for information to be collected that can inform the consumers, practitioners, and policy makers who will play critical roles in the communication and shared responsibility of services for individuals with disabilities. Variables such as diagnoses and service categories must be both universal enough to capture commonalties as well as descriptive enough for agencies to see themselves in the categories. This data collection need could be addressed through Delphi methodologies (McKillip, 1987) using panels of experts who can identify the full range of service categories that reflect the intricacies that exist nationally as well as within states. The most effective and efficient level or levels within a service delivery system at which to collect data needs to be identified. Since states vary so greatly in the way their services and data collection mechanisms are structured, an in-depth study of a sample of states could reveal a greater depth of information than was possible with this general survey. Finally, the information gathered over the course of this investigation shed relatively little light on services for individuals with developmental disabilities (such as mental retardation) within the mental health system compared with other state agencies (e.g., VR or MR/DD agencies). While we know they are receiving services there remains a great deal more to know about the types, characteristics, funding sources of services, consumer satisfaction with services, and potential for expanded services in the future. Perhaps the most valuable information gathered in this study is about what questions and challenges remain as researchers venture again into the field.

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Appendix A

Letter to Commissioners and Directors of State Mental Health Agencies

August 24, 1994

Dear «name»:

The Administration on Developmental Disabilities has commissioned the Institute for Community Inclusion to undertake a national study of day and employment services for individuals with developmental disabilities. The Institute has collected this data from state Mental Retardation and Developmental Disabilities agencies over the last six years. Through secondary analysis of the Rehabilitation Services Administration data tapes, we have been able to study the trends in services for people with Developmental Disabilities through the Vocational Rehabilitation agencies.

Previous data collection efforts have not include state Mental Health agencies. However, we feel it is important for us to begin collecting this information since many individuals with severe mental illness also meet the functional criteria for developmental disabilities. The National Survey of Day and Vocational Services through Mental Health Agencies will allow us to develop a full profile of services for individuals with developmental disabilities as well as explore trends between state Mental Health, Mental Retardation and Vocational Rehabilitation state agencies. We have enclosed a copy of the survey for your information.

We request that you designate a staff person who will serve as data co-ordinator for this survey. Kindly indicate their name on the enclosed postcard. We will address all further communication to this individual. Once the data has been collected from all fifty states and Washington D. C., we will complete a summary report and send it to your attention.

Thank you in advance for your support and participation in this ongoing data collection effort. We are pleased to be involved in reporting the scope of day and employment services for to individuals with developmental disabilities since it contributes to better planning and service provision. If you have any questions or comments about this research effort, please feel free to contact either of us at (617) 735-6506.

Sincerely,

William E. Kiernan, Ph.D.
Director

John Butterworth, Ph.D.
Research Coordinator

Jean Whitney-Thomas, Ph.D.
Research Associate

Appendix B

State Mental Health Agency Commissioners/Directors
And Survey Coordinators

State Mental Health Agency Commissioners/Directors* And Survey Coordinators**

State	Commissioners/Directors	Survey Coordinators
Alaska	Margaret Lowe	Craig Kahklen
Alabama	Richard E. Hanan	Vince Campbell
Arkansas	Ann Patterson	Tom Head, Melody Gayle
California	Steve Mayberg	Kathy Styc
Colorado	George Kawamura	Ron Eicher
Connecticut	Albert J. Solnit	Joseph H. Marcoux
District of Columbia	Guido R. Zanni	James Hubbard
Florida	James V. Laney	Bob Constantine, Brian Jacobson
Georgia	Carl Roland	Larry Walker
Iowa	Harold Templeman	Janet Shoeman
Idaho	Ken Patterson,	Roy Sargent
Illinois	Jess McDonald	Mike Mulvany, Julius Rachkus
Indiana	Robert L. Dyer	Charles Boyle
Kansas	George Vega,	Kathleen Morrow
Kentucky	Donald E. Ralph	Barbara Gordon
Louisiana	Walther W. Shervington	Tony Spire
Massachusetts	Eileen Elias	Thomas Athern
Maryland	Stuart Silver	Lissa Abrams
Maine	Roger Deshaies	Jan Halloran
Michigan	James K. Haveman Jr.	Jean Elder
Minnesota	James Stoeber	Virginia Selleck
Missouri	Keith Schafer	Jerold Pyle
Mississippi	Albert Hendrix	Tessie Smith
North Carolina	Mike Pedneau	Susie Eguez
North Dakota	Sam Ismir	Carl Rodlund
Nebraska	Dale B. Johnson	Jim Harvey
New Hampshire	Donald L. Shumway	Michael Kelly
New Jersey	Alan G. Kaufman	Steve Fishbein
Nevada	Jerry Zadny	Peter Steinman
Ohio	Michael Hogan	Michael Schroeder
Oklahoma	Sharron D. Boehler	Steve Davis
Pennsylvania	Ford Thompson	Carol Ward Colasante
Rhode Island	A. Kathryn Power	Deborah Dogule
South Carolina	Joseph J. Bevilacqua	C. Edgar Spencer
Tennessee	Evelyn Robertson, Jr	Dennis Wenner
Texas	Dennis Jones	Pamela Daggett
Virginia	King E. Davis	Michael Schank
Vermont	William Dalton	Doreen Chambers
Washington	Brian Sims	Huss Malik
Wisconsin	Sinikka McCabe	Pat Rutkowski
West Virginia	Robert Hess	Ted Johnson
Wyoming	Harvey Hillin	Carolyn M. Dennis

* The Commissioners and Directors listed above were in office in the Fall of 1994 when the project began.

** More than one survey coordinator participated in the study for a number of states. The authors would also like to thank the administrative assistants and other personnel in the state MH agencies who helped with this project.

Appendix C

Data Collection Instrument

NATIONAL SURVEY OF DAY AND VOCATIONAL SERVICES THROUGH STATE MENTAL HEALTH AGENCIES

Instructions: Please review the enclosed definitions of disability groups and vocational services . If the specific categories requested are not available, please provide as much relevant data as possible. Please fill in each space requesting information. Enter zeros if your agency does not fund or monitor a specific group or service category. Enter 'N/A' if the data absolutely are not available.

Definition

1. (a) Does your agency use the new definition of mental illness issued in May 1993 by the Center for Mental Health Services? *(See definition.)*

☐ Yes ☐ No

(b) **If no**, are you planning to use it in the future?

☐ Yes ☐ No

If yes, anticipated implementation date of new definition. _____

(c) If your agency is currently using or has plans to use the new definition of mental illness, please describe the impact this has for eligibility and service provision for your agency.

_____

_____

_____

Data Collection System

2 (a). Does your agency have a computerized management information system to track or document individuals served and/or types of services provided?

☐ Yes ☐ No ☐ Under Development

(b) **If yes**, which of the following best describes your computer resources?

___ A personal computer or PC network within your department

___ A mainframe/mini computer within your state agency/department

___ A mainframe/mini computer within a state umbrella agency or separate state agency

___ Contract out to a private agency/organization

3. Please indicate the availability of the following types of data in your state by checking the appropriate line:

	Data Available and Aggregated at the Following Level		
	State	Regional	County
1. Expenditure Data for Day/ Vocational Services			
(a) Funding Source	_____	_____	_____
(b) Service Category (e.g. supported employment, facility based work)	_____	_____	_____
2. Consumer Characteristics			
(a) Age	_____	_____	_____
(b) Gender	_____	_____	_____
(c) Ethnicity	_____	_____	_____
(d) Primary Disability	_____	_____	_____
(e) Secondary Disability	_____	_____	_____
(f) Adaptive/Functional skills related to the seven major life areas	_____	_____	_____
3. Service Data			
(a) Type of service by number of consumers (e.g., numbers of individuals receiving supported employment services)	_____	_____	_____
(b) Primary Disability **by** service type (e.g., number of people with Mental Retardation in Supported Employment)	_____	_____	_____
4. Unmet Needs Data			
(a) Number of individuals graduating who will need services	_____	_____	_____
(b) Number of individuals not receiving but waiting for services	_____	_____	_____
(c) Number of individuals receiving services who need a different service	_____	_____	_____

Individuals Served

4.(a)Please list the total number of individuals who received services from your state Mental Health agency during FY 1993. This total should include people who received inpatient or outpatient services, case management, or vocational services.

_____Total # served by your state MH agency in FY 1993

(b) Please describe what data sources were used to gather this information.

_____

_____

(c) Of these individuals in 4 (a), please estimate the number of people with Mental Illness who meet the federal functional definition of Developmental Disabilities as the result of a psychiatric disability (i.e., have a mental impairment which was manifested prior to age 22 and resulted in substantial functional limitation). *See definition sheet*

____Estimate of the # of individuals with Mental Illness who would meet the federal functional definition of Developmental Disabilities as the result of a psychiatric disability

5.(a) Does your state agency have a mechanism to identify individuals served by the MH agency who have mental retardation (i.e., people with significantly subaverage intelligence and functional limitations in major life areas, DSM IV 317-319) ?

☐ Yes ☐ No

(b). **If yes**, what coding system do you use? (i.e., DSM IV, ICD-10)

_____coding system to identify people with mental retardation

(c) **If yes**, please indicate the number of individuals who have Mental Retardation and who receive services from your state's MH agency. (This number should be a subset of the total reported in Question 4 (a))

____Total # of individuals with Mental Retardation who receive services from you agency

Day and Vocational Services

6. Please indicate, by checking the appropriate line, which of the following **community-based day and vocational services** are funded, operated or regulated by your state Mental Health agency. **Do not include those vocational services that are conducted on the grounds of a residential Mental Health hospital or facility that serves more than 16 individuals.**

_____ **Time-limited Training/Competitive Employment**
- Environment where **most** workers do not have disabilities
- **Time-limited** job-related supports or job placement services are provided to the worker with a disability in order to obtain employment

_____ **Supported Employment (with ongoing support)**
- Environment where most people do not have disabilities
- **Ongoing** job-related supports are provided to the worker with a disability in order to maintain employment

_____ **Psychosocial Clubhouse**

- Environment where most people have some type of disability
- **Primary** program focus on work ordered day, i.e., work units on site and includes option for transitional employment in the community
- Clients are not paid for participation in clubhouse.

_____ **Facility-based Work Program** (e.g., Sheltered Workshops, Work Activity Programs)
- Environment where most people do have some type of disabilities
- **Continuous** job-related supports and supervision are provided to workers with disabilities

_____ **Facility-based Nonwork** (e.g., Day Activity , Day Habilitation and Day Treatment programs)
- Environment where most people have some type of disability
- **Primary** program focus includes, but is not limited to: psycho/social skills, activities of daily living, recreation, and/or professional therapies (e.g. O.T., P.T.)
- **Continuous** supports and supervision are provided to all participants with disabilities

_____ **Programs for Elderly Individuals**
- Environment where all participants are 55 years or older
- **Primary** program focus includes but is not limited to: leisure, recreation, nonvocational activities
- **May** be integrated with elders who do not have disabilities

7. (a)Please list the total number of individuals with mental illness who received day and vocational services in the community that are funded or monitored by your agency during FY 1993.

_____Total # who received vocational programs in FY 1993

(b) Please describe what data sources were used to gather this information.

_____

_____

8. Please provide information below for the total number of individuals served in day and vocational programs that were funded, monitored or operated by your agency during FY 1993. The second column is for individuals served in these programs who have mental retardation. Please fill in each line, using "0" if your agency does not provide the service and "N/A" if data are not available. (This number should be a subset of the total reported in Question 7). **Do not include those vocational services that are conducted on the grounds of a residential Mental Health hospital or facility that serves more than 16 individuals.**

Total Served and Number Served with Mental Retardation by Service Category

Day and Vocational Services	Total Number Served	Number Served who have Mental Retardation
Time-limited/ Competitive Employment		

Supported Employment		
Psychosocial Clubhouse		
Facility -based Work		
Facility-based Nonwork		
Programs for Elderly Persons		

9.(a) For individuals with mental retardation and developmental disabilities who received inpatient mental health services in FY 1993, please rank order sources from which the person was referred. Rank order from 1 to 7, with 1 representing the most frequent referral source.

_____ Home/Family
_____ Community Residential Program
_____ Mental Retardation/Developmental Disabilities Agency
_____ Schools
_____ Social Services/Social Welfare agency
_____ Courts/Referred by judge
_____ Other (please specify_____)

(b) Please rank order the frequency of program service where individuals with mental retardation and other developmental disabilities are discharged to after receiving inpatient mental health services. Rank order from 1 to 10, with 1 representing the point of most frequent discharge program service.

_____ State operated Mental Retardation/Developmental Disability agency
_____ Privately operated Mental Retardation and Developmental Disability agency
_____ Mental Health Community Support Agency (e.g., Psychosocial Clubhouse)
_____ Nursing Home (ICF)
_____ Nursing Home (ICF-MR)
_____ Board and Room Facilities
_____ Home/Family
_____ Senior Citizen Program
_____ School
_____ Other (please specify_____)

Policy Issues

10. (a) Does your state MH agency currently have a formal plan or state-level policy to expand **integrated employment** for persons with mental illness (i.e., time-limited training/competitive employment or supported employment)? (***If no,*** *please go on to question 12.)*

☐ Yes ☐ No

(b) **If yes,** please indicate below the number of new placements that are anticipated for integrated employment programs administered by your state agency over the next 2 years (through June, 1996).

_____ # of new placements anticipated for integrated employment over 2 years.

(c) **If available,** please indicate below the number of new placements that are anticipated for integrated employment programs administered by your agency over the next 5 years (through June, 1999).

_____ # of new placements anticipated for integrated employment over 5 years.

11. (a) Please indicate below how your state agency plans to fund these new integrated employment placements.
Check one option only.

☐ (1) Use of new state or federal dollars

☐ (2) Redirection of existing state or federal dollars

☐ (3) Combination of new **and** redirection of existing state or federal dollars

(b) **If (2) or (3)** are checked in #9 above (indicating redirection of funding), please check whether funding will be diverted from the following existing day or employment service categories.

☐ (1) Funding will be diverted from existing sheltered employment/work activity services

☐ (2) Funding will be diverted from existing day activity/day habilitation services

☐ (3) Funding will be diverted from existing psychosocial clubhouse programs

☐ (4) Funding will be diverted from state hospital funds

12. (a) Does your MH agency have a state-level policy to prioritize or target specific groups for the allocation of new integrated employment services?

☐ Yes ☐ No

(b) **If yes,** please indicate how the following groups will be prioritized for integrated employment services by ranking from #1 to #7, with #1 indicating the highest priority level. If two groups will receive the same level of priority, this may be indicated by using the same ranking number. Please feel free to add any additional groups.

_____ Students transitioning from school to work

_____New adult referrals into the day/employment service system

_____Individuals currently employed in sheltered employment/work activity programs

_____ Individuals currently employed in day activity/day habilitation programs

_____ Children with serious emotional disturbances

_____ Individuals who meet the federal definition of Developmental Disabilities

_____ Other *(Please specify)*

13. If you perceive that there currently are barriers to the expansion of **integrated** employment services (time-limited training/competitive employment or supported employment) administered by your state agency, please list the three most important barriers below .

1._____

2._____

3._____

Thank you for your cooperation in completing this survey

Appendix D

Day and Vocational Service Definitions

DAY PROGRAM / EMPLOYMENT SERVICES: DEFINITIONS

PLEASE REVIEW THE SERVICE CATEGORY DEFINITIONS. IF YOUR AGENCY USES ADDITIONAL/DIFFERENT DEFINITIONS PLEASE ATTACH A DESCRIPTION.

COMPETITIVE EMPLOYMENT:

- 0 ENVIRONMENT WHERE MOST WORKERS DO NOT HAVE DISABIILITIES
- 0 ONGOING JOB-RELATED SUPPPORTS ARE NOT PROVIDED TO THE WORKER WITH A DISABILITY IN ORDER TO MAINTAIN EMPLOYMENT

SUPPORTED EMPLOYMENT (WITH ONGOING SUPPORT):

- 0 ENVIRONMENT WHERE MOST WORKERS DO NOT HAVE DISABILITIES
- 0 ONGOING JOB-RELATED SUPPORTS ARE PROVIDED TO THE WORKER WITH A DISABILITY IN ORDER TO MAINTAIN EMPLOYMENT

ON - THE - JOB TRAINING :

- 0 ENVIRONMENT WHERE MOST WORKERS DO NOT HAVE DISABILITIES
- 0 TIME LIMITED EMPLOYMENT TRAINING PROVIDED TO THE WORKER WITH A DISABILITY IN PREPARATION FOR COMPETITIVE EMPLOYMENT IN THAT JOB OR A SIMILAR JOB

WORK ADJUSTMENT TRAINING:

- 0 ENVIRONMENT WHERE MOST WORKERS HAVE DISABILITIES
- 0 TIME LIMITED TRAINING ORIENTED TOWARD DEVELOPING WORK TOLERENCE, PERSONAL ADJUSTMENT SKILLS, ETC.

SHELTERED EMPLOYMENT

- 0 ENVIRONMENT WHERE MOST WORKERS HAVE DISABILITIES
- 0 CONTINUOUS JOB-RELATED SUPPORTS AND SUPERVISION ARE PROVIDED TO ALL WORKERS

COMMUNITY-BASED DAY AND EMPLOYMENT SERVICES CATEGORY DEFINITIONS

Please review the service category definitions. Community-based day/employment services include all day or employment services except those conducted on the grounds of residential facilities with 16 or more residents.

TIME-LIMITED TRAINING/COMPETITIVE EMPLOYMENT

- Environment where most workers do not have disabilities
- **Time-limited** job-related supports or job placement services are provided to the worker with a disability in order to obtain employment

SUPPORTED EMPLOYMENT(WITH ONGOING SUPPORT)

- Environment where most workers do not have disabilities
- **Ongoing** job-related supports are provided to the worker with a disability in order to maintain employment

PSYCHOSOCIAL CLUBHOUSE

- Environement where most people have a disability
- **Primary** program focus on work-ordered day (i.e., work units on site and include options for transitional employment in the community)
- Clients are not paid for their participation in the clubhouse

SHELTERED EMPLOYMENT/WORK ACTIVITY

- Environment where all workers have disabilities
- **Continuous** job-related supports and supervision are provided to all workers with disabilities

DAY ACTIVITY/ DAY HABILITATION

- Environment where most participants have disabilities
- **Primary** program focus includes but is not limited to: psycho/social skills, activities of daily living, recreation, and/or professional therapies (e.g. O.T., P.T.)
- **Continuous** supports and supervision are provided to all participants with disabilities

PROGRAMS FOR ELDERLY PERSONS

- Environment where all participants are 55 years or older
- **Primary** program focus includes but is not limited to: leisure, recreation, nonvocational activities
- **May** be integrated with elders who do not have disabilities

CENTER FOR MENTAL HEALTH SERVICES DEFINITION: MENTAL ILLNESS

Adults or children may be considered seriously mentally ill if they have a diagnosiable mental illness that substantially interferes with or limits their performance of one or more major life area.

Considerations in defining a person's functioning in terms of mental illness are :

(1) during the past year the person has had a diagnosable mental, behavioral or emotional disorder.

(2) this disorder was of sufficient duration to meet the diagnositic criteria specified within DSM-IV.

(3) the disorder has resulted in functional limitations which substantailly interferes with major life activities:. (a) self care; (b) receptive and expressive language; (c) learning; (d) mobility; (e) self-direction; (f) capacity for independent living; and (g) economic self-sufficiency.

Persons from birth to age eighteen who meet these criteria are considered to be children with serious emotional disturbances.

Persons from age eighteen and older who meet these criteria are considered to be adults with serious mental illness.

FEDERAL FUNCTIONAL DEFINITION: DEVELOPMENTAL DISABILITY

The federal definition of the term 'developmental disability' means a severe, chronic disability which:

a. is attributable to mental or physical impairment or combination of mental and physical impairments;
b. is manifested before the person attains the age of twenty-two;
c. is likely to continue indefinitely;
d. results in substantial functional limitations in three or more of the following areas of major life activity:
   (1) self care;
   (2) receptive and expressive language;
   (3) learning;
   (4) mobility;
   (5) self-direction;
   (6) capacity for independent living, and
   (7) economic self-sufficiency; and
e. reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

OVER

MENTAL RETARDATION

The 1992 AAMR definition of Mental Retardation is:
"Mental Retardation refers to substantial limitation in present functioning. It is characterzed by significantly subaverage intellectual functioning, existing concurrently with related limitations in 2 or more of the following applicable adaptive skill areas:

(a) communication
(b) self-care
(c) home living
(d) social skills
(e) community use
(f) self-direction
(g) health and safety
(h) functional academics
(i) leisure
(j) work

Mental Retardation manifests before age 18."

Appendix E

Technical Notes for Table 3

Technical Notes for Table 3

Total Served by State

North Carolina: The number of children who fit the MR definition is 7,981.

Oklahoma: The number provided represents clients whose primary diagnosis is mental retardation and not those whose secondary diagnosis is mental retardation.

Virginia: The 21,645 individuals with diagnoses of MH and MR served through the Virginia MH agency includes 18,990 served in community-based services and 2,655 served in state facilities.